NATIVE AMERICAN COMMUNITY SERVICES OF ERIE AND NIAGARA COUNTIES, INC.

"A Tradition of Caring"

NATIVE AMERICAN TRAINING INITIATIVE (NATI)

Community Input Report

...we are all interconnected to one another,
when we lose one person it affects the entire community.

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James Knapp, Executive Director

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Project Staff:

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EXECUTIVE SUMMARY

The Native American Training Initiative (NATI) was developed to increase the capacity of HIV educators throughout the state to meet the needs of urban Native Americans and Native people living within the nine Native American Nations. NATI was funded by the Centers for Disease Control and Prevention and was charged with gathering information for inclusion in a Native American cultural competency training for non-Native HIV educators. The project provided an opportunity for Native people across the state to share their ideas about effective approaches to providing HIV prevention to Native Americans.

Qualitative data was gathered from Native American communities through a series of community input meetings and use of an individual input questionnaire. From late 1994 to early 1995, a total of 132 people attended community input meetings at eight separate locations: the Shinnecock Reservation, New York City, the Akwesasne Mohawk Nation, the Onondaga Nation, the Tonawanda Seneca Reservation, Buffalo, the Tuscarora Nation, and the Seneca Nation of Indians at the Allegany Reservation. Additionally, a total of 41 individual input questionnaires were returned by members of various Native communities. This input was later used in the curriculum development process for the cultural competency training.

NATI also recruited a representative Native American Curriculum Review Committee to assist the AIDS Institute's Educational Services Section in developing the one day training entitled **Empowering Native American HIV Educators.** Curriculum Review committee members and NATI project staff also served as Native American co-trainers for this regional training, held in five locations across the state in September, 1995.

From the community input process, a general consensus emerged around several key issues regarding cultural competency training for non-Natives and HIV education for Native peoples. The Native American communities expressed strong agreement on ten major points:

- Native American service providers and community members make the "best messengers" to deliver HIV/AIDS prevention messages.

- Trained Native American "messengers" possess cultural understanding, direct access to the community, and can effectively communicate the prevention message.
- Potential Native American "messengers" need to receive appropriate training in HIV and AIDS prevention.
- A culturally relevant HIV education curriculum for Native Americans should:
  - use non-confrontational approaches.
  - express traditional Indian values.
  - use humor.
  - avoid stereotyping any group or community.
  - be flexible enough for use with all community groups and sub-populations.
- Native American community members can play an important role in identifying and training key community leaders to educate others about HIV. Key community leaders include: Clan Mothers, Elders, traditional leaders, staff at health service and alcohol and substance abuse programs, and other community programs.
- Support materials that would be most effective include:
  - literature with a Native American orientation.
  - materials that incorporate both traditional and contemporary perspectives.
  - video tapes that can be viewed independently.
  - community newsletters (and other forms of outreach).
- Non-Native HIV/AIDS professionals need to be aware of the importance of respecting the sovereignty of Indian Nations and the right of these Nations to direct HIV prevention education which takes place on Nation land.
- Training in cultural competency for non-Native HIV educators should focus on understanding unique Native American community values.

- Community perceptions of potentially high risk behaviors were identified as alcohol and substance abuse, unprotected sexual activity, and loss of traditional Native American values and teachings, which have resulted in social irresponsibility.
- Emphasizing the need to provide HIV prevention education, community members cited three key justifications:
  - it would protect future generations of Indian populations.
  - it would provide an urgent message to youth to ensure their understanding of the magnitude of the problem.
  - it would diminish fear and rejection of community members living with HIV/AIDS and help facilitate their acceptance and/or return to the community.

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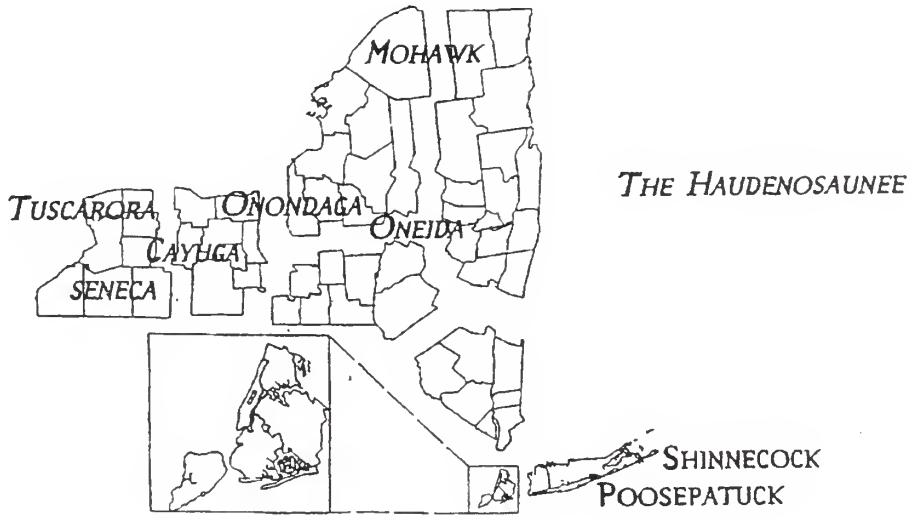

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Eastern Area

The first community contacted was the urban American Indian population living in New York City, which is composed of Native Americans representing a wide diversity of Indian tribes that are indigenous to North America. The New York City meeting was attended by: community members; staff from the American Indian Community House (AICH), including its Executive Director, Rosemary Richmond; our project consultant, Curtis Harris, and members of the Native American Leadership Commission on Health and AIDS (NALCHA).

During this eastern trip, the NATI Project also met with members of the Shinnecock Indian Nation, located near Southampton, on Long Island, New York. In attendance at this meeting were representatives of the

Department of Health Indian Clinic and Community Health Worker Program, youth programs, Title V Indian Education Program Education staff, members of reservation-based church groups, members of the Shinnecock Community Council and community members in general.

Mid-State Area

There were two additional Indian communities visited in the mid-state meetings, which included the Akwesasne/St. Regis Indian Nation and the Onondaga Indian Nation. Representatives attending the Akwesasne/St. Regis Indian Nation meeting included: the St. Regis Indian Health Services staff; Community Services Director, Rita Swamp; ACT NOW (HIV testing/counseling provider) staff, Lynn Herne and Sandra Jacobs; Partridge House (substance abuse in-patient treatment facility) representative, Allen Herne; other alcohol/substance abuse service providers; Family Services staff; Education staff; school counselors; nurse educators; and youth program directors.

Immediately prior to the meeting held with the general population at Onondaga, the NATI Project coordinator met with the Clan Mothers from the traditional governments of the Six Nations. Since Clan Mothers are the most important conduit of information flowing to the people, this was an important opportunity to provide them with basic information about the project. A Clan Mother, usually the oldest woman in a clan (or extended family), is responsible for the welfare of her clan members. Clan Mothers routinely distribute information to the community, contact individuals when problems arise, and give direction to their chief, who sits in Traditional Council on their behalf. Therefore, this opportunity was critical to the success of the project. The general consensus among those present was that HIV and AIDS prevention training is important and should be given to the health clinic professionals and any other groups that can provide information and support to the communities.

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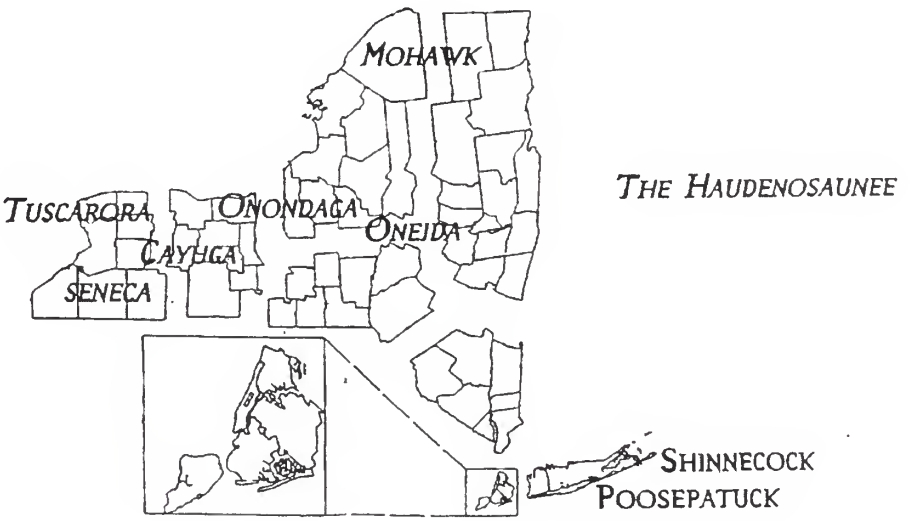

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substance abuse prevention; and Leon Shenandoah, Faithkeeper of the Six Nations Grand Council, who provided the meeting with an opening and closing prayer.

Western New York Area

In the Western New York area, there were four meetings held with: the Buffalo Niagara Falls urban Indian community; the Seneca Nation of Indians; Tonawanda Band of Senecas; and the Tuscarora Indian Nation. The largest of these meetings was held at Native American Community Services' (NACS') Buffalo office, attended by: members of the Buffalo and Niagara Falls communities; NACS representatives from HIV Prevention Services, Alcohol/Substance Abuse Prevention, Employment and Training, and Youth Services; a NACS board member and professor at SUNY Buffalo School of Social Work; a school counselor with the Akron Central School District Title V Program, a representative from Erie County Department of Social Services; and community Elders.

A meeting was held at the Seneca Nation of Indians Council Chambers with President Dennis Bowen and members of his Health Services staff. The timing of this meeting with President Bowen was ill-fated in that the ruling Tribal Council had just attempted to impeach him in a proceeding the previous week. In speaking with President Bowen about the HIV/AIDS Training Project, he indicated how important he believed our effort to be to the welfare of Indian people. Having recently returned from working in community services programs in Arizona, he shared the concern that he believed Indians in general were at great risk and needed more information to be shared across professional disciplines to spread the prevention message. Despite limited attendance at this meeting, there was a great deal of information forthcoming from Health Department staff regarding their efforts to inform the public on HIV and AIDS prevention.

The Tuscarora Indian meeting participants, which included two Indian Health Clinic professionals, five Clan Mothers, and two community members, were generally supportive of the NATI Project. Deferring to the

health professionals, individuals generally agreed there was a need for training of all health and community services workers and the development of more culturally-appropriate prevention materials. The NATI project's plans to develop culturally appropriate prevention materials were explained, comments taken on the questions regarding culturally sensitive curriculum, and concern was expressed for the youth populations.

The Tonawanda Seneca Nation meeting was very upbeat. Two of their Community Health Workers were present and described their innovative methods of providing information using less direct means. Condom distribution was incorporated into their medicine distribution program, HIV and AIDS prevention videos, pamphlets and protected sex literature are being provided on a very successful and systematic basis. The Tonawanda Seneca Youth Program staff started a project approximately three years ago, providing sex education, counseling and information on alcohol and substance abuse to a broad spectrum of students in the Akron Central School system. The Community Health staff work very closely with the Indian Health Clinic staff, which provides them an opportunity to access individuals in their homes. Meeting with individuals on a one-to-one basis facilitates confidentiality and eliminates any possibility that other Health Clinic patients will overhear their conversation. As presented, the Tonawanda Seneca program offers a valuable paradigm that other State-operated Indian Community Health Worker Programs could emulate.

Although the urban Indian communities of Rochester and Syracuse were contacted, neither returned questionnaires, nor attended the regional input meetings at Buffalo and Onondaga Nation, respectively, as originally arranged. The Native American Cultural Center of Rochester indicated that their population declined to participate because they were uncomfortable with completing a questionnaire. This was an anticipated result and was the reason that open input meetings were held instead of distributing a survey within the Native American populations. The Oneida Indian Nation also did not respond to inquiries and requests for participation in the project.

METHODOLOGY

To make this report user-friendly, key issues identified through the community input process have been addressed in question and answer format to effectively summarize the qualitative value and general consensus of the responses. The remainder of the questions generated similar responses that were able to be compiled and correlated.

The following was used to discern the prominent trends in community input:

1. The first step in the methodology was to delineate specific categories of input information and compare the answer to responses given by members in other Native American communities.
2. To determine whether a consensus existed on any particular issue, the total number of individuals at each meeting was added to the total number of written surveys submitted from the urban and reservation communities. A matrix was then created to identify the extent of consensus on a particular survey question.
3. When a significant positive correlation was established, it was inferred that a consensus of agreement on a given response was present among the communities; differentiation between communities could be established by the absence of a consensus; or that a curriculum element, community issue or societal norm was important or prevalent within the sample population.

Using this methodology, the aggregate number of participants was ascertained to show the extent of agreement on a given issue. This method did not adapt to data on beliefs. Since the project did not ask direct questions related to belief systems, the information obtained was gleaned from conversation content, discussion opinions or commentary offered by participants and reported as general statements of belief.

The number of participants and completed questionnaires at each of the meetings were: NYC (35); Akwesasne Mohawk Nation/St. Regis (41); Buffalo urban community (30); Onondaga Indian Nation (18); Shinnecock Indian Nation (2); Tonawanda Seneca Indian Nation (15); Tuscarora Indian Nation (10); and the Seneca Nation of Indians(4). No responses were returned from the cities of Syracuse or Rochester, or the Oneida Indian Nation. The explanation given by the American Indian Center in

Rochester for their non-participation was consonant with what had earlier been communicated at the first NATI/Department of Health meeting in Syracuse at the outset of the project: Indian people generally will not participate in surveys, nor complete written documentation upon request. For this reason, the method of input meeting was established to permit narrative summaries as opposed to survey statistics.

Questions asked at the Community Input Meetings, and a summary of the consensus of responses, is as follows:

COMMUNICATION

"Who is the best messenger for HIV prevention education?"
Overall, women were identified most frequently as the best messenger in both urban and reservation communities. Nation Clan Mothers and Elders were the second most frequently mentioned 'best messenger." This consensus was most apparent in traditional Nations (the Onondaga, Tonawanda Seneca, and Tuscarora communities), where Elders and Clan Mothers are viewed as having a duty to teach communal responsibility to community members.

In the two elective systems sampled (the St. Regis Mohawks and the Seneca Nation of Indians), health/community services programs were listed as the "best messenger" because these programs routinely interfaced with state agencies that provide funding. Similarly, urban communities saw health professionals as appropriate messengers.

Additional consensus among traditional communities found school, health programs, parents and community service programs as possible messenger opportunities. HIV/AIDS consumers, alcohol anonymous and Al-Anon were seen as the least viable alternative. Urban communities demonstrated similar results in that input identified school, health and community service programs as potential channels of information.

"How do we access the messenger?"
Methods to access the "best messenger" within Indian communities are generally not discussed with non-Native representatives. Frequently, Indian governments do not respond to inquiry from outside agencies. Therefore, the most important element in building effective communication with a traditional government is to establish official contact between the Indian Nation Council and the State agency representative. To outreach the Indian Health Clinic or Community Services Workers for training, appropriate letters should first be sent to the Indian government. Simultaneous to this contact, the Director of the NYS Department of Health Native American Health Program should become involved to open

communications with local Indian Health Clinics or agencies responsible for administering the program. Once contact with the Indian leadership has been established, it would be appropriate to request from the Council the recommendation of an individual who might serve as the messenger.

In urban Indian communities, "accessing the messenger" is usually accomplished through the Indian cultural or community center which is often located in proximity to an urban community of Indian residents. In most instances, connecting with the urban Indian community can be accomplished through outreach to the leadership.

"What aspects of the Native American culture can be used to promote risk reduction?"

In identifying what aspects of the culture were important, all participants listed multi-generational respect for Elder wisdom, which is one reason that these individuals were viewed as one of the best messengers. Other cultural aspects also found to be important included the following: community responsibility to protect future generations; Indian traditional beliefs and values; and the closeness of Indian communities that requires trust in anyone who would deliver the message. Less mentioned was the need to develop a holistic approach in designing a culturally relevant curriculum.

"What communication style works best?"

Overwhelmingly, all Indian respondents indicated that a non-confrontational style would work best with their community members. Non-directive approaches that allow the client or patient to seek information at their own comfort level were viewed as the best means of providing embarrassing sex education or detailing the use of protective devices. In the Tonawanda Seneca Community Health Worker Program, individuals obtaining condoms on a routine basis are not required to identify their needs other than to request another prescription of their "medicine," which is handed to them in a standard medicine container (brown bag).

"What do we need to know about styles of communication among Native Americans?"

In responding to this question, the traditional communities indicated that inter-communications between cultures were strained and reserved. This view was not shared by urban Indian programs, nor the elective systems of St. Regis and the Seneca Nation of Indian program representatives. Almost

all of the community members found that humor should be used in communicating with Indian consumers, stating that styles need to be relaxed and casual. Most also warned that non-Natives should try to use little eye contact, primarily because Indian people avoid direct, confrontational discussion, contrary to the Euro-American view that eye contact denotes attentiveness. The reservation communities suggested that communication should occur in the community on a one-on-one basis. This would facilitate flexibility, privacy and ensure personal contact. At least half of all communities saw the use of storytelling as a means to better communicate a message.

"What kind of support materials work best?"

In approaching this question, the consensus among both urban and reservation Indian communities indicated that literature which had an Indian orientation would work best to communicate the prevention message. There was unanimous agreement among community members that teaching materials that were adapted to an Indian motif would enhance learning. A mixture of both traditional and modernist views saw sex education materials about condom use and/or abstinence were necessary and in at least one traditional community health clinic, video tapes were being disseminated privately to the homes of community residents. The video tapes on HIV and AIDS were returned to the Community Health Worker when they revisited the home.

Other suggestions included developing a community newsletter, using arts and culture to effectively communicate among the Indian culture, mailings, pow wows, and health fairs as possible contact opportunities.

"How useful are materials developed in Western states for Natives in Eastern states?"

Each urban and reservation Indian population is different from another depending on their geographical location. The Six Nations have a unique intra-government and intra-community relationship among their people. All six of the Nations have a common origin (indigenous to the east coast); their languages are similar; and their culture and customs are closely related because they follow the traditions of the Great Law of the Haudenosaunee. In discussing cultural differences between the Six Nations and other tribes from the South or Northwest that might require

the development of unique materials, community members remarked that although the "other ways" of different Nations were respected, they were nonetheless recognized as not being "our way." An example of one such custom is the use of the sweat lodge as a purification ceremony. Therefore, it is important to bear in mind that posters, traditional healing practices and counseling that might be suitable for other Indian communities may not be effective with the Six Nations, Shinnecock, or the urban Indian communities of the State.

"What is the best way to get to know Native American communities?"
One way to effectively outreach Indian members living in urban or reservation populations is to spend time in or visit the communities. Generally, visitation in a reservation community might require initial contact with the respective nation government to obtain permission or an invitation. Where there are Indian Health Clinics or IHS facilities, it is likely that relationships between these operations and State agencies have already created a channel of communications. This relationship can be used to obtain information on the appropriate way to contact the government.

In accessing an urban Indian community, establishing contact with the existing community center or cultural program would provide the necessary introduction to community life in the city. Accessing the residents thereafter would be the result of cooperative programming or visits to the existing center.

"What tribal organizations would be helpful?"
Local educational programs were identified as the primary agency to convey prevention training. Most participants expressed that community-based education through youth services programs would be a productive way to utilize peer training and had a high potential for success. A significant number of community members thought that the Native American community-based health services could contribute, working with the Clan system—Clan Mothers, Elders and traditional leaders. A lesser consensus formed around alcohol/substance abuse programs and Indian cultural programs or groups as potential resources.

"How do you find the gatekeepers?"
Indian communities, like other cultural or political enclaves, are rarely open to "outside" or invasive interference. This was expressed at the

Onondaga Indian Nation meeting by a community member who reminded the project representatives that their Nation was separate and not a part of the State. Therefore, in order to find the "gatekeeper", formal communication should be established between governments or program directors, developing the kind of a relationship through which this question can be asked of the urban or reservation community representatives. The general consensus among reservation communities was that the Indian health personnel needed to be included, as did the Elders, Clan Mothers and Faith Keepers. In some instances, the need to involve traditional community leaders was also reflected in urban communities (NYC).

"What important segments of the Native American community should be addressed?"

In all communities, youth were seen as a critical sub-population to be targeted. Not only did many communities see this group at particular risk, youth are also the embodiment of the "Seventh Generation." In many traditional cultures, decisions are made in the context of their impact seven generations into the future; in this way no harm can come to the Creation. The welfare of youth, consequently, is critical to the continuation of the people and culture.

Other key sub-populations identified in several communities included alcohol/substance abusers and men who have more than one partner. The Native gay community was identified in New York City as highly under served.

The second portion of this question: "Should different approaches be used with these different groups?" was not addressed during the input sessions. However, it is important to realize that there is a need for established political protocol which is generally followed in communicating with reservation communities. While elective systems of government such as the Seneca Nation of Indians or the St. Regis Tribe also require formal protocol be followed, access to their government structure is somewhat easier. Outreach to the community residents of urban centers can be enhanced and facilitated by obtaining the cooperation and assistance of the Indian community service agency.

"How can educators make HIV education culturally relevant?"
A strong consensus developed around certain elements of a culturally relevant HIV education curriculum. All community input sessions recommended the use of Native American trainers/educators to ensure the effectiveness of the trainer/member communication. Most agreed that educational materials would inspire understanding if they expressed traditional Indian values. Many community residents (urban and reservation) thought that parents should be involved since it was "their responsibility to teach the children."

There was agreement that HIV education should use a holistic approach, or a cross-generational program with traditional healing messages. Half of all participants thought that educators needed to be "up-front", use clear language or communicate in the language of the particular Nation. Slightly less than half of those providing input warned against the use of guilt or fear, and many thought that personal experiences of individuals would be useful.

"What are the barriers to effective HIV education—state, community, cultural, regional, personal?"
There was strong consensus that barriers to effective HIV education might arise where personal and family dysfunction were a factor. Many cited strained Indian/State relations as a prohibiting influence in creating an effective prevention message. Another barrier, community bias against HIV and AIDS, was viewed as a potential interference to a successful HIV education effort. Slightly more than half saw cultural differences as a major cause, while only a few saw regional differences as a factor.

ATTITUDES AND BELIEFS

"What are the attitudes of Native Americans about health care?"

Health care services among Indian communities are perceived differently depending upon the location, particularly in reservation-based communities that have their own health clinics. Many Indian Health Services and New York State Department of Health (NYSDOH) clinics are under-utilized, although consumer usage is increasing in these facilities overall. Nonetheless, many community members indicated reluctance to use the HIV testing services of such facilities. Many feared that confidentiality and/or anonymity would not be possible within the context of a community-based clinic where everyone is known. While health care through the presence of clinics is perceived as a treaty obligation, strong consensus appeared from the reservation communities that recommended the use of outside agencies for HIV testing.

"What is the current level of knowledge among Native Americans about HIV?"

About two-thirds of the participants indicated they believed that knowledge of HIV was increasing within their communities. A small number stated that they knew little or nothing about HIV, and an even smaller group thought they were well informed about HIV.

"What do people believe about the origins of HIV?"

Although not much was expressed about the beliefs regarding the origins of HIV, when the topic was mentioned, a few individuals identified homosexual activity as the source, and some believed it was imported from Africa. It was often mentioned in traditional communities that the development and spread of HIV was foretold by Indian prophecies.

"How do these beliefs affect prevention?"

Prevention education will be hampered if the belief persists that only homosexual behavior initiates HIV infection. It is vital to the prevention effort that health professionals clarify the type of sexual activity or threshold behaviors that expose individuals to the virus. The fastest growing American population of HIV positive individuals is heterosexual youth. Not unlike the American youth population, this group of individuals feel invulnerable to the disease. Given the concern expressed throughout the Indian communities about the future generations of their young, the youth

population should be included in any education effort, as well as the middle-age and elder populations.

"What do people need to know about HIV?"
There is a strong consensus among all communities that people need to know that HIV can be sexually transmitted through unprotected heterosexual activity, and that injection drug use is yet another potential source. Respondents also wanted people to know that you can live with the HIV virus, and that self-care prolongs the life of a person infected with the virus.

"What do Native Americans believe about sexuality and homosexuality?"
Although not directly addressing this question, urban and reservation participants discussed the rejection of homosexual lifestyles within their communities. NYC residents expressed acceptance and stressed understanding for "two-spirited" individuals. In general, members were less inclined to openly discuss their sexuality. Overall, this reticence was more commonplace among men than women. While it was universally perceived that women were primarily responsible to protect themselves from infection or disease through sexual contact, it may be very difficult to follow through with this responsibility when their partners are either reserved or outright refuse to discuss the issue of protection.

"How do HIV educators build trust with the community?"
Responding to this issue, the consensus was that trust could not be established in an HIV educator unless that individual was a member of the community. Trust was seen as "essential" in dealing with all community members whether they resided in urban or reservation areas. Suggestions that were given to build trust included becoming familiar with the community through contact; learning about Indian values and respecting "our ways"; working with populations over a long period of time; and maintaining confidentiality of individual clients, patients or consumers. Both the traditional and elective system representatives indicated that outreach to the health agencies and cooperative efforts would enhance the opportunity to build trust within the community.

"Are there stereotypes of Native Americans that should be shattered?"
Stereotyping of Native individuals was not discussed by meeting participants. A group of community members from a particularly strong traditional nation indicated that they should not be perceived as "having disappeared as a people," stating that "we are still here, sovereign and want what the treaties have promised—good health care and education." If non-Natives have an image of Indian people as submissive societies, it would be important that this particular impression be adjusted to include the more realistic view—that Indian members are firmly resolved to ensure the safety of their future generations and require that State agencies address this issue.

Generally, Indian people have comparable aspirations, are motivated to work, go to school and have families. They often experience similar difficulties with job loss, lower income, periodic unemployment, a need for more schooling or retraining. An inordinate number have serious health problems, and need more and better medical care. Their cultural philosophy or 'way of life" is to accept things as they are and not resist or engage in activism. Nonetheless, it was apparent at all community input meetings, that the health and safety of their youth populations was paramount among their concerns regarding HIV and AIDS.

"How do the traditional spiritual beliefs of Native Americans affect the delivery of HIV prevention services?"
The spiritual beliefs differ from community to community. Strong traditional populations (Onondaga, Tonawanda Seneca and Tuscarora) are communities that maintained their societal integrity where extended familial and societal concern for the health and welfare of all individuals is of primary importance. However, even urban communities (such as Buffalo and NYC) exhibit this type of concern for community members. Since confrontational type behaviors are avoided in the spirit of cooperation, it may be more difficult for health or education professionals to broach uncomfortable subjects with patients or students. Therefore, other methods to disseminate information in a non-confrontational manner will need to be developed. Confrontation was seen as potentially destructive to social cohesiveness. Therefore, to effectively communicate prevention messages, the messengers (state/health/education program staff) must be uni-

fied, and able to convey in a non-threatening manner the importance that prevention measures will have on their collective well-being.

"What are the attitudes of Native Americans about government agencies and government involvement in their lives—local, state and federal?"
Among all the reservation communities there was strong consensus that Indian Nations are sovereign and have the right to determine who would provide services for individuals within their territories. While the presence of NYSDOH clinics or Indian Health Centers were viewed as indispensable, recommendations were made pertaining to the following: their Indian health or clinic programs should coordinate services with other health programs; they needed help to train their own people; they wanted the governments to share statistical information on the number of HIV and AIDS cases among Indians; and they requested assistance in resolving family dysfunction or other crises in their communities. This last issue was clearly expressed at the St. Regis meeting where it was shared that the proliferation of alcohol and substance abuse problems in their youth populations have resulted in significant social disruption. A program staff person from the ACT NOW organization expressed alarmed concern regarding the need for State funding, as increasing numbers of individuals request HIV testing through their program.

"Describe the history and values of Native Americans and how they effect HIV education."
One community member summed up Indian values as, "We are all interconnected to one another. When we lose one person it affects the entire community." In short, Indians care about other Indians, whether they have enough to eat, a decent place to live, guidance if they are a child, and assistance if they are an elder. Indian communities are unique in that they will live or die dependent upon how each individual member upholds their personal commitment to the society. If Indian people are to survive, it will be the result of a cooperative effort by responsible members who care about sustaining the lives of everyone through prevention.

Some of the more traditional communities expressed their lack of trust when they stated, "Our history has taught us that when the whites give us something, they want something in return." It is therefore paramount that the communities understand that prevention education and HIV/AIDS

information has no reciprocal trade-off requirement such as statistical data regarding the incidence of the infection within a population, or other objectionable activity in which a health service may subsequently engage.

"What are some of the sensitivity issues regarding the use of Native cultural ceremonies and activities by non-Natives?"

Although this question was not directly addressed, community members did recommend the use of traditional health methods, ceremonies and the holistic approach to well and self-care training. Since the ceremonies are religious rituals that are not open to non-Natives, discussion on the use of specific ceremonial ritual was avoided. It is not reasonable to assume that non-Native individuals from the outside could be trained in or given access to these ceremonies. However, in some Indian populations (urban and reservation combined), there are traditional groups that interface with the alcohol and substance abuse programs. These groups are using the 'sweat lodge ceremony" as a purification mechanism to cleanse the spirit. Although, this activity is not regarded as a traditional Six Nations Haudenosaunee ceremony, it has been adopted by some societies and is being practiced to strengthen the spirit of individuals in recovery. It is possible that the prevention message could be carried to some of these groups with the permission of their organization and participants.

"What interaction is there between traditional Native culture and Western culture, and how has traditional culture changed or adapted?"

Participants indicated they believe that Indian culture is dynamic and has adapted to meet the changing needs of Indian societies. Discussing this reality appeared to cause great concern among the participants, many of whom indicated that they see traditional values as sustainable societal norms to shape today's communities. Participants realized that on a daily basis, Indian children were exposed to educational systems that provided them with modern attitudes and mainstream American social values.

In this respect, compulsory education was viewed as corruptive to traditional Indian values. Many community members indicated that they are fighting to maintain their culture. Both urban and reservation communities expressed concern that the stressful conflicts over social values would ultimately result in the cultural genocide of future generations of Indian youth.

"How do the pressures of traditional culture and Western culture affect a person's desire, willingness and motivation to learn about HIV/AIDS risk reduction?"

Representatives from both urban and reservation communities indicated that they understand the magnitude and complexity of providing prevention information to Indian members. Methods of communication appear to be of great concern. How the message is packaged is also seen as important—without cultural competency, and when not delivered by a trusted and visible community member—the message is likely to go unheeded. It does appear that more involvement in the Western culture has instigated less adherence to traditional teachings, and generated less willingness or motivation to change the high-risk behaviors to protect oneself against HIV infection. Many participants were guarded in their predictions for success. Nonetheless, the general consensus was that regardless of the presence or absence of spiritual beliefs held by individuals, the reality of HIV and AIDS is already in their communities and the health agencies, governments and populations need to deal with it as soon as possible.

PERCEPTIONS OF COMMUNITY RISK FOR HIV

"What are the primary routes of infection that concern Native Americans?"
The consensus of all participants was that the primary route of infection among Native American people was unprotected sexual behavior.

"What are the primary risk behaviors among Native Americans?"
The general consensus regarding primary risk behaviors identified alcohol and substance abuse as a primary factor leading to HIV infections.

"What co-factors put Native Americans at risk for HIV?"
Respondents unanimously agreed that the use of alcohol and substance abuse was a primary co-factor placing Native Americans at risk of HIV infection.

"What is the general state of health among Native Americans?"
Nationally, according to the Indian Health Service's Trends in Indian Health 1992:

In 1986-1988 the Indian (IHS Service Area) age-adjusted mortality rates for the following causes were considerably higher than those for the U.S. All Races Population:

1) tuberculosis — 480 percent greater
2) alcoholism — 388 percent greater
3) accidents — 185 percent greater
4) diabetes mellitus — 169 percent greater
5) homicide — 91 percent greater
6) suicide — 52 percent greater
7) pneumonia and influenza — 42 percent greater

Of those responding, most community input indicated the belief that the state of health of Native Americans was generally poor. Accompanying this belief were several comments on the inadequacy of health care as provided by the Department of Health Clinic facilities. Indian Health Services programs were viewed as under-funded, with reductions or an absence of increases as the major cause.

"Who are the Native Americans in NYS?"

According to the 1990 U.S. Census, there are over 60,000 Native Americans living in the State of New York. The Haudenosaunee, or Six Nations confederacy, are aboriginal to what is now upstate New York. Comprised of the Mohawk, Oneida, Onondaga, Cayuga, Seneca, and the Tuscarora Indian Nations, they make up the large majority of Native Americans living here today. Significant concentrations of Native Americans reside on the various Nation territories, surrounding areas, and in the cities of Syracuse, Rochester, Buffalo and Niagara Falls. There are two Indian Tribes on Long Island, which are the Shinnecock Indian Nation and Poosepatuck Tribe. Approximately half of the State's Native population resides in the New York City area, and is comprised of Native people from a wide diversity of Native Nations. A significantly larger number of Native Americans in New York State reside in off-reservation areas.

OTHER

"What do Native American educators need to know about HIV/AIDS?"
Almost all community members expressed the idea that Native American educators needed to know basic HIV information for training, such as: the incidence, primary causal factors, prevention methods, and personal health maintenance.

"What is the best way to recruit Native American educators?"
Community members stated that the best way to recruit Native American educators would be through contact with the government (as in the case of reservation communities); or through existing health care or community services agencies (urban or reservation communities).

"What are the differences between reservation and non-reservation populations?"
Generally, reservation communities are geographically and politically separate from the outside communities. Although the cultures in these communities have experienced great change during the last twenty years, most respondents still viewed their communities as uniquely different from the American mainstream. The essence of that uniqueness might be seen as stubborn resistance to not becoming "Americanized." Most respondents saw their "Indianness" as a relationship to the land. This identity has been largely shaped by societal learning, and has a tendency to remain with the individual even where that member migrates into the urban population. Researchers have distinguished Indian cultural values as: caring more about harmony with others in the society than maintaining individual priorities. It also was seen to include: the presence of interrelated family support systems that include multi-generational involvement of extended family and friends; subordination of one's own will or goals for the benefit of the Indian community; and a self-effacing manner that fails to bring recognition or prominence to a part rather than the whole. It would be wrong to impute differences between reservation and non-reservation Indians since the community input received from urban populations indicated that their perceptions of their beliefs, values and relationship to their former society were quite similar to the Indian member who resides within the reservation.

RESOURCES

The American Indian Community House, Inc.
HIV/AIDS Project
404 Lafayette Street - 2nd Floor
New York, NY 10003
212/598-0100

AICH Outreach Education Coordinator Network
306 South Salina Street, Suite 201
Syracuse, NY 13202
315/478-8532

AICH Sewenaka Place
573 Roanoke Avenue
Riverhead, NY 11901
516/369-8082

ACT NOW
Akwesasne: HIV/AIDS Information and Resource Center
Box 747
Hogansburg, NY 13655
518/358-2001

Walk in Self-Harmony (WISH)
306 South Salina Street, #201
Syracuse, NY 13202
315/478-3767

Vision Quest
2495 Main Street, Suite 524
Buffalo, NY 14214-2103
716/832-2303

Native American Community Services of Erie and Niagara Counties, Inc.
1005 Grant Street
Buffalo, NY 14207
716/874-4460

American Indian Law Alliance
404 Lafayette Street, 2nd Floor
New York, NY 10003
212/598-0100 ext. 257

National Native American AIDS Prevention Center
2100 Lake Shore Avenue, Suite A
Oakland, CA 94606
510/444-2051
1-800-283-6880

National Indian AIDS Information Line
1-800-283-2437
M-F, 8:30 a.m. to 5:00 p.m. PCT